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REVIEW

Psychological responses and support needs of patients following head and neck cancer

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Head and neck cancer;
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Abstract The patient with head and neck (H&N) cancer is prone to psychological distress immediately following diagnosis and during the treatment phase. Lowered mood is typical and tends to extend beyond the treatment phase. There is little evidence for a specific treatment method predicting a characteristic psychological response. Rather, patients' reactions vary widely according to fears of recurrence, health beliefs, personality, coping and available support. Patient reports of quality of life show a return to pre-treatment status after a year but are determined to some degree by initial depression levels and dispositional factors such as optimism. Information provided to patients (e.g. leaflets, booklets of written guidance) by specialist treatment centres about the disease and its management require sustained effort in their design and distribution. Our understanding of patient responses to this disease has improved and has assisted in the development of psychological interventions. Controlled trials will provide important evidence of the components, effects and sustainability of these experimental programmes, and improve overall care plans for this often neglected patient group.
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Introduction

The treatment of patients diagnosed with head and neck (H&N) cancer presents challenges to the surgical team. Successful outcome is assessed by traditional survival rates and by additional factors notably morbidity, functional status and quality of life (QoL). The assessment of QoL is salient when the differences in survival rates between different treatment regimens are marginal. The decision on the method to select may then be indicated by patient preference or known QoL improvements. Recently, the literature on outcomes has extended to related issues including: psychological status and a discussion of what patients experience during the recovery and rehabilitation phase. This article presents a brief review of current knowledge in this expanding field for clinicians performing highly individualised treatments. The aim of this brief review is to highlight the

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important factors that will assist in helping to select the most beneficial treatment pathway for the patient with H&N cancer.

Head and neck cancer is the sixth most common cancer worldwide.[1,2] Ninety per cent of these cancers are squamous cell carcinomas. Men are more likely than women to succumb to the disease by a ratio of 3:1. The disparity between the sexes is becoming less pronounced in the U.K. Mortality rates are high at 54% overall.[3,4] Also, recurrence rates are high in the first year following diagnosis of the primary tumour, compared to many other cancers.

Detection and treatment

Primary care doctors detect most tumours on complaint of soreness in the mouth or throat by their patients. However, on enquiry GMPs preferred that this task associated with any oral symptoms should be the major remit of the dentist.[5] A number of psychological factors explain the delay of patients with advanced H&N cancer seeking medical care. Patients who delay more than 3 months tend to be less optimistic, less committed or involved in health activities (termed 'health hardy'), cope less actively and seek less support, compared to those who seek medical attention within 3 months.[6] The management of H&N cancer relies strongly on surgery or radiotherapy, or their combination (see Fig. 1).[7] Surgical intervention aims to completely remove the primary cancer and any involved lymph nodes. Preservation of function is a secondary aim and finally the maintenance of aesthetics. Many H&N cancer patients are treated with high-dose radiotherapy, which as a consequence also irradiates associated sensitive tissues such as mucous membranes, nerves and circulatory structures.[8] Increasing intensity of treatment has produced significant improvements to outcome but has raised side effects.[8] Delay (greater than 6 weeks) in starting radiotherapy following surgery has been shown to be detrimental to 5-year local

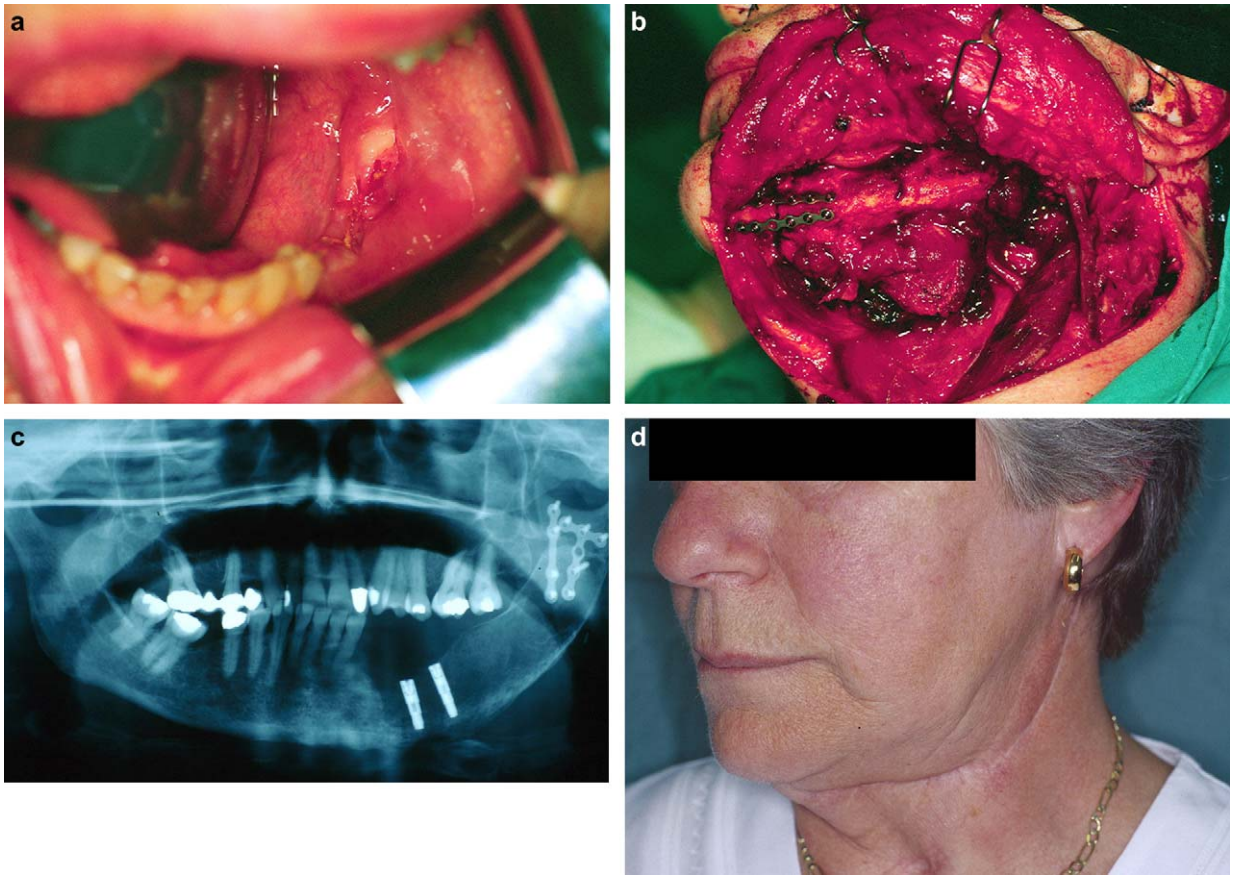

Figure 1 (a) Squamous cell carcinoma of the left posterior mandible. (b) Mandibular resection with reconstruction. (c) Postoperative panoral radiograph showing placement of plants and implants. (d) Six months post surgery, showing good aesthetic results.

recurrence rate.[9] Primary tumour location and disease stage are known to influence treatment selection but not co-morbidity or pre-treatment QoL.[10]

Psychological morbidity associated with diagnosis and treatment

An important threat to the overall well being of patients with H&N cancer is increased psychological distress.[11,12] The level of psychological morbidity in patients with this cancer has been studied.[13–15] H&N cancer patients who have serious disease or who live alone were found to be more likely to suffer psychological distress (odds ratios of 5.77 and 4.83, respectively). The immediate impact of diagnosis and treatment is an important phase for detailed study.[16]

A high incidence of anxiety (35%) soon after diagnosis and peak levels of depression (30%) about 3 months following initial treatment have been reported.[16] Anxiety rises soon after diagnosis, whereas depression takes 3 months to reach a peak. The rates of both constructs return almost to pre-treatment level by 12 months. Humphris and Rogers[17] showed comparable rates at 3 months following treatment. Distress (30% 'cases') has been found in long term survivors (>6 years).[18] The use of self-rating scales may underestimate the effects of treatments as detailed interviews have revealed greater levels of distress in a reported in-depth study.[19]

Factors that influence psychological distress

A number of psychosocial variables have been clearly implicated in the development of anxiety and depression in this group. These include: information needs, fears of recurrence, quality of life, self-care behaviour, coping, personality, appearance, and social support.

Information needs

Patients vary considerably in the extent of the information that they wish to receive from health care providers.[20] Some evidence suggests that the adequacy of information received by H&N cancer patients has implications for positive recovery some 2–6 years later.[21] In addition, in a review of psychological factors related to QoL it was concluded that information needs were especially pertinent as these were modifiable.[22] Although patients may not appear to exhibit detailed knowledge of the options available for treatment, or the recommended practices for rehabilitation and aftercare following initial treatment, they will have their own beliefs and expectations. These may be based upon the experiences of family members and/or friends who may have suffered from other cancers. Hence, the range and types of treatments that these associated supporters may have experienced could differ significantly from those recommended to the patient with H&N cancer. Patients frequently suffer undue anxiety because they find the treatment incomprehensible. The uncertainty is partially a function of the limited supply of information in a form that the patient understands.[23] A number of authorities and voluntary groups have produced electronically accessible versions of leaflets and booklets aimed at patients at all stages of the diagnostic and treatment process. However, it is not known whether the typical H&N cancer patient will have access or the computer skills to utilise these resources.

In a recent study, a selected sample of H&N cancer patients reported that they were relatively well informed about the surgical treatment they received but felt less prepared for the extended lifestyle changes. Information and guidance during the 3–6-month postoperative period needed to be improved. The patients did not sense that there may have been a chance for them to express an opinion over a possible choice of treatment. Those who expressed a wish to be active in this way felt they could not obtain the necessary information to assist them in this more active role which could involve discussions, for example, of survival trade-off for maintaining greater function.[24]

Recurrence fears

Once treatment has been completed and the patient discharged, both patient and carer may express relief. However, this eagerly awaited step can generate anxiety and distress.[25] The stage has been referred to as the 'neutral time' when recurrence fears surface.[26] Some evidence suggests that fears of recurrence are a major concern,[27] and in one survey fear of recurrence was the most frequently ranked concern of 13 concerns listed.[28] Furthermore, patients treated for a malignancy not less than six months previously, 42% reported that fears of recurrence were their greatest concern.[29] Maguire and colleagues have shown that health-related concerns have the potential to cause depression.[30] An episode of depression can be precipitated when these health concerns are resisted expression during contact with the health care services.

A cognitive formulation has been proposed to explain how patients' fears of recurrence are raised.[31] Strikingly, the patients described their experience of recovery as being peppered with frequent false alarms triggered by unusual sensations, including tingling, pins and needles, rapid swelling, and sensitivity to hot and cold. These sensations were interpreted as indicators of new symptoms and the return of the cancer. This pattern of experiences fits the Common Sense Model of Illness developed by Leventhal and colleagues where physical symptoms may trigger emotional reactions such as fears of recurrence.[32–34]

A high incidence of recurrence fears is unrelated to the extent of the disease or when the diagnosis was made has been reported.[35] Two years later these fears are found to be relatively stable ($r_s = 0.7$).[36] The point prevalence of concerns about the cancer returning is 65% in both the baseline and 2-year follow-up samples. This is consistent with other reports of long-term survivors of H&N cancer.[37]

Though the risk of recurrence is a vital issue for patients, this concern is not always immediately obvious to the clinician.[38] Patients may keep recurrence concerns to themselves or deny the possibility of a recurrence. Staff may collude and avoid discussing the topic of recurrence.

Quality of life

In the H&N cancer field patients' QoL research has increased rapidly.[39] A range of measures specific to this cancer have received critical review[39] and associated studies presented.[13,40] Much of this literature has focused on single issues. For example, long term QoL appears not to vary greatly with age of patient. Such a finding would support providing identical treatments to all age groups.[41] Likewise, dental status has an impact on the QoL of 5-year H&N cancer survivors.[42] Some attempt has been made to convert raw QoL scores to more meaningful clinically significant benchmarks, which will strengthen the adoption of these assessments.[43]

A Swedish longitudinal study of QoL has been reported[44] including anxiety and depression indices. Two-thirds of the patients remained alive to study completion. The health related quality of life (HRQoL) scales attained their lowest level immediately after treatment. Virtually all of the subscales returned to their pre-treatment levels within a year. Dry mouth, sexual responsiveness and dentition were resisted improvement over time. After 1 year post treatment the HRQoL levels remained relatively stable. Mental distress and global quality of life were the most significant improvements over the 3-year duration. Depression and physical functioning at baseline predicted independently global QoL at 3 years. Patients with advanced disease (Stages III and IV) scored poorly on virtually all HRQoL domains. Other longitudinal studies tracking HRQoL adopting standardised instruments have reported a rise of QoL on virtually all domains to pre-treatment levels after 1 year post treatment.[45]

Raised depressive symptoms at pre-treatment predicted similar difficulties at 6 and 12 months later, including physical functioning.[46] Prediction of depressed status was 81% and 67% at the two time periods, 6 and 12 months respectively. These percentages increased to 89% and 82% if the patients' physical symptoms at the time of assessment were entered into the explanatory model. The routine screening of psychosocial variables and physical symptoms before treatment are recommended to identify patients who may be susceptible to depression on recovery from surgery and/or radiotherapy for H&N cancer.[47]

An interesting finding in a 6-year longitudinal study with H&N cancer patients was that the intensity of a number of psychosocial complaints, such as feeling angry, irritable, tense, and anxious, were significantly associated with remaining recurrence free.[21] The only other variable that had a greater predictive power was extent of nodal metastases. A further report has shown that patient reported QoL is related to survival. Pre-treatment fatigue was a significant predictor of survival for patients with advanced H&N cancer.[48]

Self-care behaviour

An important study of self-care behaviour (e.g. grooming)[49] showed that in a matter of days, those patients who started looking after themselves made faster recoveries. Patients who tried to cope and re-socialise needed to view themselves close up (in a mirror), touch their own facial defects, and expose them to others.

Coping

The commonest coping mechanisms demonstrated in H&N cancer patients are helplessness and fatalism (70% of patients).[27] Resolution of concerns occurs in less than 40% of the frequent concerns expressed. Paradoxically, it is not the most seriously ill patients who cope poorly. Some patients, especially those with more advanced H&N cancer develop more problem-focused coping abilities to manage the adverse effects of treatment on their global QoL.[50] Patients appear to exhibit a wide range of positive strategies to cope but they

may be poorly applied. These may be encouraged however, through support-based interventions.[51]

Personality

The disposition of H&N cancer survivors has been shown to have some long-term effects on mood, QoL and survival. Patients with H&N cancer reporting a 'sense of humour' at diagnosis tend to be less depressed 6 years later.[52] Pre-morbid pessimism in 5-year survivors was the strongest predictor of QoL measures over physical risk factors (e.g. shoulder and neck range of motion).[53] Dispositional optimism predicts 1-year survival in this patient group independent of socio-demographic and clinical variables.[54] Surgical teams are advised to take account of these character traits when organising their treatment plans and follow up support.

Appearance

There is considerable variation in the concerns that patients express about appearance changes.[55] West argues that the time spent on the ward with others of similar status prepares the patient for discharge into the social world on leaving the hospital.[56] Other investigators have alerted clinicians to unspoken distress from scarring and disfigurement caused by surgery or radiotherapy. A survey of patients over 18 months[57] found that extensive disease involving neck dissection to remove involved lymph nodes had a strong negative effect on appearance ratings. Tumour size was less strongly associated with appearance, but those with larger tumours tended to rate themselves less positively than those with small tumours.[57] This work is consistent with a Canadian study where patients were found to show a strong association between the level of disfigurement and depression.[58]

Social support

The interpersonal relationship of the H&N cancer patient with their spouse/partner seems an important determinant of whether to seek consultation initially. In addition, the ability to sustain a recovery from the treatment of H&N cancer is crucially dependent on the level of support to which the patient has access.[59] Both surgery and radiotherapy to the face and neck influence important structures responsible for the self-image of the individual.[60] In addition, the ability of the patient to resume social activity can be markedly undermined. This particular cancer challenges many ways that patients may wish to communicate. Available support has been shown to lead to less depressive symptomology in patients followed from diagnosis to 6 months later.[61] This association was strongest in patients with few physical complaints. Received support, however, was unrelated to depression, leading the authors to believe that support may be detrimental in those with few physical complaints. The provision of support, therefore, needs to be targeted appropriately rather than offered indiscriminately.

Psychological interventions

There have been many calls for introducing greater emotional support for H&N cancer patients.[12,27,62,63] Pilot work describing the design and implementation of two types of intervention have been reported with some encouraging preliminary results.[64] The first tested the effect of long-term group psychotherapy with newly diagnosed patients. The greatest improvement was emotional functioning in the intervention group compared to the controls. The second study investigated a 1-week psycho-educational programme delivered 1 year following surgery. Positive changes on anxiety and depression were reported. Both interventions require randomised controlled studies to confirm these effects.

A psychosocial support programme was evaluated with H&N cancer patients using a longitudinal, prospective, case-control design.[65] The support programme consisted of visits from the cancer team, including a weekly visit during treatment and then once a month for the first 6 months following treatment, and then again 1 and 3 years after diagnosis. At 1 year follow-up the control group had a clinically and statistically better global QoL score. This difference was not sustained at 3 years. One explanation offered was that the study group patients became dependent on the visits as satisfaction levels with the intervention were high at 1 year whereas QoL did not improve. The authors stressed the need for improved training for hospital personnel to recognise patients with affective disorders. In support of this view, a further intervention to improve nutrition in patients with H&N cancer only found a significant longer term effect on QoL when the advice given was delivered by a counsellor.[66]

The 'adjustment to fears, threat and expectation of recurrence' (AFTER) intervention was designed to identify and reduce patients' fears of recurrence following primary treatment for orofacial cancer.[17] The intervention consisted of six structured sessions to be delivered by a specialist nurse and featured the encouragement of the

patient to express their concerns over future disease. The randomised controlled trial to test the intervention demonstrated a short-term effect that reduced cancer worries, anxious preoccupation and increased global QoL. To the authors' knowledge at the time of writing there are two major psychologically based RCTs with H&N cancer patients. These are being conducted in Montreal, Canada[67] and Utrecht, The Netherlands (de Leeuw and coworkers), and will provide further evidence for the role of structured psychological support.

Conclusion

The surgeon faces many dilemmas when approaching the treatment of the patient with head and neck cancer. Not only are there numerous decisions to take surrounding the surgical plan but also the total care package will include reference to wider issues including the psychological status of the patient. This review has introduced some of the key factors that clinicians should be aware of to ensure the overall health of the patient. Attention to detailed assessment within the team to maintain an individualised approach and also to introduce more systematic and targeted service provision such as psychological interventions are considered as achievable aims for improving head and neck cancer services.

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